



Prostate Cancer: Decision Aid Video for Patients

Grant Number: R44CA62808-03

Abbreviated Abstract

Prostate cancer affects an estimated 317,000 men and results in more than 41,000 deaths annually. Treatment options range from surgical removal of the prostate to active surveillance. Men diagnosed with prostate cancer are confronted with a difficult decision, which they are often ill-informed to make. Decision Aids are educational tools designed to help patients make informed, satisfying decisions about medical treatments. The goal of this SBIR is to produce and test a videotape about treatment options for prostate cancer that presents medically rigorous information in non technical language using documentaries of real patients. The primary goal is to promote informed decision making about treatment as well as to increase patient satisfaction with their decisions. During a successful Phase 1, we developed a script and a 7 minute video excerpt based on feedback from men treated for prostate cancer, their partners, urologists, and nurses. In Phase 2, we will: (1) produce the full length videotape, (2) assess its appeal by conducting focus groups with patients treated for prostate cancer, their partners, and medical professionals, (3) assess its effectiveness in a clinical setting by conducting a field test with men diagnosed with prostate cancer, and (4) develop and initiate a plan for the distribution of the video.

Primary Investigator

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Dr. John McKinlay, NERI's Senior Vice President and Director, is an internationally respected epidemiologist/medical sociologist with interests and experience in public health, epidemiologic field studies, clinical decision making and health policy. He was for several decades a distinguished academic and an administrator (at Boston University) holding simultaneously Professorships in Medicine, Biostatistics and Epidemiology and Sociology and directed both BU's Center for Health and Advanced Policy Studies and its Gerontology Institute. He has been a consultant to the Division of Medicine at the Massachusetts General Hospital (Harvard Medical School) for 30 years. Among his numerous awards and honors are an NIH MERIT Award, an American Psychological Association award for ADistinguished and Pioneering Contributions to Research on Women's Health@ and the American Sociological Association's Leo G. Reeder Award for ADistinguished Contributions to Medical Sociology@. Dr. McKinlay is the author, co-author or editor of over 250 professional papers and 17 books. He has been at the forefront of milestone developments in his fields: is one of the first to relate social support networks to utilization behavior; the first to trace the historical transition from professional dominance to physician corporatization and to identify its consequences; is an early proponent of prior demonstrated effectiveness as a basis for resource allocation (later known as

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Aevidence-based medicine); a co-developer of the first scientifically valid health risk appraisal (the AHA=s RSKO); and he is at the forefront of the exciting movement to develop a Anew public health.” Dr. McKinlay is Senior Vice President and Director of NERI’s Community Health Studies Research Dr. McKinlay maintains an extensive portfolio of research in community-based epidemiology, male endocrinology, clinical decision-making, health disparities and healthy public policy.

Research Team & Affiliations

John McKinlay, PhD – NERI PI; Robert Krane, MD (dec) Massachusetts General Hospital (Co-I); Lisa Marceau, MPH – NERI (PD); Steve Braun – NERI (Writer)

Total Budget

\$703,962.00

Research Objectives

Aim 1: To produce an educational video on the treatment options for prostate cancer;
Aim 2: To evaluate the effectiveness of the video in transmitting accurate information about prostate cancer and in aiding these individuals in making decisions related to treatment;
Aim 3: To further develop distribution outlets.

Theory/Hypothesis

- Due to limited physician-patient interaction at point of diagnosis, patients often receive information at the time of diagnosis (maximum stress with minimal retention);
- Information is conveyed only once;
- There is variability in the quality and objectivity of the information (a particular treatment modality may be advocated);
- Busy subspecialists frequently delegate communication tasks to others; and
- The partners of patients may not be involved. These problems could be corrected with a state-of-the-science Decision-Aid videotape which a patient receives upon diagnosis and takes home to view in the privacy of his home with his partner.

Experimental Design

Homogenous focus groups were held with matched with racially/ethnically appropriate moderator

Final Sample Size & Study Demographics

Six focus groups were conducted in July 2001. The groups were homogeneous by ethnicity and age group, one with younger (under 60 years) and one with older (60 years and over) members of each ethnic group. Men previously diagnosed with prostate cancer were recruited to the focus group study through a urologist’s office and associated Veterans Administration Hospital in Miami, Florida. Miami was selected ensure age and racial/ethnic diversity as well as access to public and private transportation.



Data Collection Methods

See Evaluation Methods – Focus group

Outcome Measures

Focus groups were used to evaluate this product. To understand how a decision aid can help in making treatment choices, recognition of what is important to patients was essential. Prior to viewing the videotape, the focus groups were asked to describe how they made their treatment decisions. Five major topic areas were identified as critical considerations in making treatment choices. Anticipated side-effects, potential success of the procedure, reoccurrence or metastases, and the relative ease or speed of the treatment

Evaluation Methods

To assess the impact of the videotape on African American, Latino and White men recently diagnosed with prostate cancer, we undertook a qualitative study with focus groups. This method was selected to explore their observations and reactions, yielding information about the salience and perceived value of the videotape. Qualitative methods have high external validity for information about social experiences and emotional reactions because they allow the researcher to gain an understanding from the subject's point of view. This is critically important in a study involving men from distinct cultural backgrounds.

Three focus group moderators, matched to their groups by ethnicity, were trained to use a standardized discussion guide. Participants were asked to read and sign an informed consent form and complete a brief demographics questionnaire. The focus group sessions were divided into three segments. The first began with series of questions about the participants' experiences with their own diagnosis and decisions about treatment. They talked about how they obtained information, assistance with decisions, difficulties they experienced, and how they viewed each treatment option. The groups then viewed the videotape. In the third segment, the groups discussed their reactions to the videotape. The two-hour sessions were tape-recorded and transcribed to written form.

The transcripts were analyzed using common coding techniques applied in qualitative analysis. The transcripts were entered into QSR NUD*IST 3 software for whole text analysis. The analysis proceeded in iterative steps. First, two coders independently read the transcripts identifying themes within each transcript. Secondly, the segments of text within each transcript were identified and compared to ensure consistency of definitions for the themes. Third, sub-themes (topic areas) were identified and coded.

Research Results

Findings suggest that men who are diagnosed with prostate cancer need and want considerable help with understanding their diagnosis and treatment options. Commonly expressed concerns included:

- Lack of understanding about diagnostic test information and their prognosis;
- Potential side-effects of a treatment choice;
- Likelihood of success of a particular treatment approach;
- Potential for recurrence or metastases; and



- Ease and speed of the treatment. Results indicate that the program offered a systematic comparison of the treatment options in an easily understandable and interesting format; the information was covered objectively; it could be reviewed outside of the doctor's office with partners, where a patient feels more comfortable and better able to absorb information.

Barriers & Solutions

Product(s) Developed from This Research

Making the Right Choice: A Decision-Aid Video for Prostate Cancer
La selección de su terapia, Spanish version